

BOOK REVIEW

# *The Better End: Surviving (and Dying) on Your Own Terms in Today's Modern Medical World*

by Dan Morhaim, MD

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Karen Ann Quinlan, Nancy Cruzan, and Terri Marie Schiavo didn't know one another and lived miles apart, yet their names will remain permanently joined. Each of these young women became a *cause célèbre* and shared in a similar series of unimaginable events. Massive brain damage left each of these young women persistently vegetative, hovering in that netherworld of rousable unconsciousness. Meticulous medical and nursing care, feeding tubes, antibiotics, ventilators, and protracted legal wrangling bequeathed many additional birthdays to these young women before they were permitted to complete their dying. None ever imagined the awful fate they shared. None had documented the kind of care they would want in such circumstances.

Dan Morhaim, MD, internist and emergency physician, is a member of Maryland's House of Delegates. He wrote *The Better End* as a physician, policymaker, and bedside witness to the terrible distress that can result when people have not expressed their preferences for the care they would choose when very ill or closing in on life's end. He wants his readers to avoid the uncertainty and struggles the Quinlan, Cruzan, and Schiavo families faced. He writes to empower, advising us to talk about the kind of care we would want with those whom we trust, to appoint a surrogate or proxy decision maker to speak for us when we cannot, to document these discussions and decisions, and to provide after-death instructions for organ transplantation, body disposition, and funeral arrangements. Taking these steps does not guarantee but does increase the odds of having our voices heard and getting the kind of care we would want. They also relieve others from the burden of making complex decisions without our participation. In an era when chronic conditions and technology make the timing of death more foreseeable, preparing an advance directive is increasingly more critical.

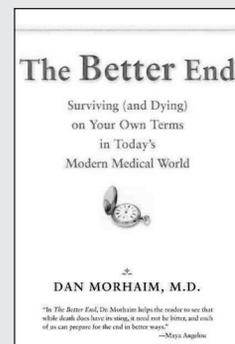
Throughout the book, Morhaim underscores the consequences of not completing an advance directive and thereby appointing someone to act on our behalf if and when we are unable to make our own treatment choices. He informs us by telling stories, including those of Quinlan, Cruzan, and Schiavo, to convince his readers that there is a *better way*. He reminds us that Quinlan's family wanted to discontinue the ventilator moving air into her lungs. They eventually won the right to stop her medical treatment, discontinued only the ventilator, and chose to leave in place the tube that delivered fluids and nourishment. She lived for almost a decade longer. Cruzan's family wanted to remove her feeding tube but was not permitted to do so. It was a long and very winding road before the US Supreme Court finally defined the constitutional right to refuse medical care including feedings. The ruling left some discretion to states allowing them to deny this right, *if an individual had not exercised it in clear and convincing terms*. Eventually after hearing new testimony, a Kansas court concluded that Cruzan had exercised her right and had expressed her desire never to be left in the condition in which she was suspended. The feeding tube was removed and she quickly died. Schiavo's case followed the others.

Her parents and husband had differing opinions, leading to a dispute over who had the right to make treatment decisions, followed by trials, multiple appeals in state and federal courts, removals and reinsertions of the feeding tube, and even special Federal and State legislation. Fifteen years after her collapse, and after a final legal ruling that upheld the decision to remove her feeding tube, she finally died.

Contemplating our own deaths and thinking of a world without us is disquieting for most Americans. In some cultures even talking about death remains taboo or at a minimum believed to be very unlucky. For some, any sign of life is preferred to death's finality. Others never want to be burdens or to be kept alive when quality of life evaporates or physical and cognitive functions fail. Morhaim recognizes the great diversity in people's values, preferences, and beliefs. He points out that regardless of our preferences the critical act is to guide and to inform decision makers by documenting our choices in one of the many tools or formats the book lists in its resource section. He emphasizes the importance of appointing a trusted proxy decision maker, pointing out that even no decision is a decision.

This book focuses on the importance of advance directives and provides valuable guidance. Deeper discussion and more illustrative stories about the challenges families and proxy decision makers may face when attempting to be true to documented preferences would strengthen the book. Proxies need to be well informed about this possible eventuality and be prepared to confront it. Medicine's authority, culture, and traditions are very strong and proxy decision makers may face strong headwinds as they attempt to honor advance directives. Clinicians must be aware of their own values, preferences, and conscious and unconscious biases and guard against inappropriately superimposing them on others. Medicine's own culture has a bias toward continuing to treat and "do one more thing" especially when a patient is younger. When people are very old and wizened, the bias can be toward less treatment.

Finally, it is important to remember that Morhaim's "better end" is one in which individuals control treatment choices through an advance directive and proxy decision maker when they no longer are able to do so themselves. It does not mean choosing palliative care or hospice over full treatment or vice versa. Labeling the former as a *good death* and the latter as a *bad death* misses the point. ❖



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